



Working With Families Who Have Special Needs

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Introduction

Principles

People with disabilities should experience love, friendship and continuity in their lives. As with all people, they have ups and downs, peaks and valleys, favorable and unfavorable reactions to events in life.

People with disabilities should participate as valued members of their communities. They should have the opportunity to advocate on their own behalf, make choices about where to live, work and recreate, and participate in other activities that contribute to their well-being.

People with disabilities have a right to receive services from public and other agencies that ordinarily provide services to South Carolinians. Those services should be coordinated with extra services they may need because of their disabilities.

Philosophy

The SC Department of Disabilities and Special Needs encourages individuals and families to be involved in planning and coordinating services and supports. Families, local county disabilities and special needs boards, service providers and DDSN regional centers will mutually accept responsibility for each individuals welfare.

DDSN will support people with disabilities and / or their families in their

efforts to care for themselves or their family member at home.

Individual/Family Participation

Individuals and families are encouraged and expected to participate in service plans and decision-making. Individuals and families should attend staffings and work with with professionals as members of the program team.

Individuals and families should be encouraged to join consumer / family organizations and participate as advocates for people with disabilities.

If prevention and in-home support cannot meet personal and family needs, residential services will be provided. When residential placement is necessary, families should continue to be actively involved. Family members should purchase clothes and personal items, participate in staffings monitor progress and discuss future service needs.

Service Agency Responsibilities

DDSN and county DSN boards ensure people with special needs and their families that everything possible will be done to provide and coordinate services for people who need them throughout their lives.

While citizens may receive services from more than one agency and may move from one type of service to another as needs change, county DSN boards will coordinate these services and ensure that they are adequately provided for each person.

DDSN will provide services to supplement those provided by regular state agencies in the following priority:

1. Prevention of primary and secondary disabilities whenever possible;
2. In-home support to help people with disabilities live in their own homes when ever possible;
3. Supported community living in individual and small homelike settings when the need for residential placement is determined unavoidable;
4. Care in regional residential centers.

Family support will be closely coordinated among the numerous public and other agencies providing resources and services to individuals and families. DDSN will work to give individuals and families more opportunities to make choices about which services and supports they receive whenever possible.

Family support services include, but are not limited to: service coordination, day services for adults and children, supported employment, early intervention, kiddie coach services, child care services, respite care, recreation services, financial assistance, in-home therapies, transportation, summer services, attendant care, homemaker services and personal care aides.

Involving Individuals and Families

'...If we're going to be successful with families, we're going to need to reorient as professionals. We're going to need to look to families as leaders, families as experts, families as bosses. We're going to need to ask them to join us cooperatively as equals in this partnership so that we create a reality there that matches what all of us want to see.'

- Lisebeth Vincent

Involving individuals and families requires change and takes time. Individuals and families should be given unconditional, positive recognition for the important job they are doing. Over time, involvement should increase individual and / or family feeling of control. Families should be encouraged to promote independence for people with disabilities and other family members. Professionals should provide nonjudgmental support and access to information for individuals and families to help them become involved.

Providing Family-Centered Services

There are three driving forces of service delivery: system-centered , consumer-centered or family-centered. DDSN is working to provide family-centered care.

Family-centered care is based on the principle that individual family strengths and needs drive service delivery. Family-centered services:

- Recognize that family is constant in a person's life, while service systems fluctuate;
- Facilitate family / professional collaboration at all levels of services;
- Honor racial, ethnic, cultural and socioeconomic diversity of families;
- Recognize individual family strengths and respect different

methods of coping;

- Share complete and unbiased information with families on a continuing basis and in a supportive manner;
- Encourage family-to-family support and networking;
- Recognize and meet developmental needs of infants, children, adolescents and adults, and their families, into service systems;
- Create policies and programs that offer families emotional and financial support;
- Offer accessible, flexible, culturally competent and responsive services.

Source: Adapted from Key elements of Family-Centered Care, National Center for Family-Centered Care, Association for the Care of Children's Health.

Working With Parents Who Are Just Learning of Their Child's Disability

When parents learn about obstacles in their child's development , the information comes as a tremendous blow. One mother described her experience as entering a dark tunnel with little hope for the future.

Family experiences are unique, but families often have common questions when learning of a child's disability, such as:

- What cause my child's disability?
- Did I do anything to cause my child's disability?
- What did I do to deserve this?

- How could God allow this to happen?
- What will my child be able to do?
- Will my child need support forever?
- Who will take care of my child when I am gone?
- How will this child's disability affect my marriage?
- How will my spouse, my other children, my extended family, my friends accept this child? Will they love my child?
- Will I be able to provide for my child's needs?
Will I be a good parent?
- Can I love this child?
- Will my child outgrow those special needs?

When learning their child has a disability, some common reactions include:

Denial - "This cannot be happening to me, to my child, to our family."

Anger - Aggression toward the child, personnel or family members.

Fear - Suspicion of the unknown and future.

Guilt - Concern about what caused the problem.

Confusion - Not fully understanding new terminology or what is happening. Confusion results in inability to make decisions, and mental overload.

Powerlessness - Inability to change what is happening.

Disappointment - Imperfection poses a threat to their ego and values.

Rejection - Rejection directed at the child, person or family. Some parents report a "death wish" for their child.

It is important for families to identify all potential feelings that may arise so that they will know that they are not alone. All parents experience feelings of inadequacy at one point or another. The difference for parents of children with special needs is that feelings of inadequacy are greater and last longer. Professionals should support families and provide hope, so that they will not feel isolated and alone.

To be more effective in working with parents who have just learned that their child has special needs:

- Present a balance between reality and hope.
- Don't withhold information. Tell the parents as soon as possible, even if you only suspect a problem. This is not the time to use the phone for communicating.
- Schedule uninterrupted time and find a quiet, private place to meet as soon as possible. Have both parents present and invite extended family members if the parents want them.
- Build trust and rapport. Be honest and straightforward as well as compassionate.
- Tell the parents they have done nothing wrong.
- Acknowledge your own feelings. Don't rush through an explanation. Encourage parents to ask questions.
- Don't inject negative thoughts about the individual with disabilities or project doubts of the family's ability to handle challenges.
- Avoid negative connotations. For example, one should not say, "Down Syndrome is mental retardation." Instead, tell parents "Down Syndrome is a chromosome abnormality." Then tell parents the other characteristics of Down Syndrome, including mental retardation.
- Allow parents to express emotions, as well as time alone to

grieve. Recognize that their feelings are, in all probability , very normal.

- Recognize the child as a "child first," pointing out normal and positive factors as well as disabilities. Always refer to the child by name.
- Encourage bonding between the baby and his or her parents. Set an example by touching, holding, smiling at and talking to the baby. Show respect for the child as a individual.
- Don't describe how much worse it might have been. At this point, the only who really matters is their own.
- Admit you don't know all the answers. Express a willingness to search for answers.
- Demonstrate to the parents that they are needed as partners. Invite them to participate in decisions and care of their child. Participation will instill confidence in the parents.
- Know about community resources to assist the child and family, giving a message of hope. Link the child and family to social and medical support groups.
- Encourage the family to take advantage of respite care to take care of themselves.
- Make sure parents have a "primary provider" to help them sort information from many specialists.
- Repeat explanations several times during the early weeks and months as parents do not absorb everything at first. You may want to tape your explanation with the parents questions and answers. Be available for additional contact and set an appointment for initial follow-up.
- Recommend that they see other parents. Get permission to give their name and phone number to a parent support group that can reach out to them.
- Take into account the families ages, educational levels and social conditions.
- Be sensitive to family needs, absorb new information and

exploring new options. Let the parents set the pace.

Note : Respect the individual and apply age-appropriate references to teenagers, young adults and others even though they are the child of a parent.

Working Together Routinely

It is important to meet the needs of the individual and their family at their level by supporting them in the family setting. Determine individual / family needs and expectations and how DDSN and / or other agencies can meet these needs.

Families who have a child with a disability need information about the disability, service, laws and policies to help with their child. They also need support to live together comfortably while meeting everyone's needs.

After you help the individual and the family identify their needs, determine the best way to gain services and help the family obtain them. Be creative in seeking alternative funding sources and / or services to meet their needs. Always keep in mind that people on waiting lists are not receiving services or having immediate needs met.

It is important that each individual and / or their family should know that you are genuinely concerned about them. Show concern by routinely calling the individual and / or their family, not just in crisis situations. Return phone calls the day you receive them, or at least by the next day.

Should you resign, call the individual and / or their family to let them know you are resigning. If you know your replacement or the person who will be working with them until your position is filled, give them that information also.

Parents like to receive feedback about their child's progress and activities they can do to reinforce skills at home. Families of individuals who attend DDSN day programs should receive this information at least monthly. Encourage parents to meet with staff to discuss concerns and / or suggestions that they may have.

If working with families of preschool or school-age children, be sure that they understand you are a resource they can depend on in developing their child's individual education plan (IEP) or individual family service plan (IFSP).

Be well-informed about services and resources from other agencies in the community. Inform, encourage and help individuals / families receive services and resources like Medicaid, SSI, local health and / or mental health services, social services, etc.

When meeting with people who have disabilities and their families, treat them with respect. Maintain eye contact with the individual and give them the opportunity and time to respond to your questions.

Other ways to improve your working relationship with people who have disabilities and their families are listed below:

- Schedule meetings at a convenient time. Agree on the day, date, time and place of each meeting. Schedule meetings when everyone who has an interest can attend.
- Before meeting, write down points and questions that need to be discussed and decisions to be made.
- Be on time for meetings. Time is important to individuals and their families.
- Focus on strengths - everyone responds best to a positive approach. Keep negative thoughts in perspective.
- Be sensitive to emotions, be supportive and "family-friendly." Show concern for the individual and family.
- Discuss needs and strengths while being respectful of dignity and privacy.
- Allow the individual and/or their family to decide if they want help and what kind.
- If you do not know an answer, get assistance from another professional.
- Make assistance match the individual's need.
- Encourage feedback from individuals and families.

- Promote open communication and provide opportunities for people with disabilities and their families to:
 - learn new skills;
 - learn more about each other's priorities;
 - share information;
 - learn each other's style of communication.

Individuals, families and professionals must understand each other. Undefined or vague terms can be a problem. Individuals and families need lay terms to help them understand, as well as technical language to communicate with professionals and research a particular condition.

- Let individuals and families tell you about themselves. They have vital information to share. They see the whole person - strengths and challenges, likes and dislikes.
- Don't blame individuals or families for problems, but encourage participation and involve them in decision-making.
- Help individuals and families see themselves as agents of change.
- Assume each person and/or family is strong and can become competent - build on what they already know.
- Provide informal support.
- Be flexible and creative about program plans, resources and funding.
- Be sensitive to personal and family priorities for:
 - programs;
 - style, time commitment, cultural values, preferences, resources.

Individuals and family members are responsible for implementing the service program and daily care. Professional recommendations must be balanced with personal and family priorities. Professionals must work together with individuals and families to establish a reasonable service plan. Without balance, programs may place unrealistic expectations and demands on individuals and families. Home care plans may not be implemented, and families may experience guilt and

frustration.

- Tell individuals and families about their rights regarding:
 - eligibility for services;
 - confidentiality and access to information;
 - informed consent;
 - grievance procedures and rights of appeal;
 - policies, principles and standards governing service delivery.
- Help individuals and families find others who have had similar experiences, even if a formal support group isn't available.
- Give individuals and families control. The individual or their family is the final decision-maker. Professionals need to support, not replace, individual and family roles.
- Believe that all problems have solutions. Allow time to help. Don't give up. Turn problems over to others when what you are doing doesn't seem to be successful.
- Remember: The individual/family is always right.
- Develop relationships with individuals and families before you need them.
- Learn to accept criticism, even hostile criticism, from individuals and families. Dealing with criticism is part of your job.
- Always let individuals/families know when something negative or positive has happened, *especially* when something negative has happened.

How To Resolve Conflicts

Individuals and families may become angry when they do not feel their needs are being met or that you are not working on their behalf. Recognize and accept their feelings. Take time to discuss their concerns. Seek help from your supervisor and/or other agencies if needed. Never threaten to have a person discharged or dismissed from a program or service because they or their family complain.

If you disagree: 1) focus on the individual's best interest; 2) emphasize what's right rather than who's right; and 3) begin with areas of agreement and work from there. When your views of "reality" differ, explore both views to understand each other's concerns.

Separate the people from the problem. People problems frequently fall into three basic categories: perception, emotion and communication. If perceptions are inaccurate, look for ways to educate. If emotions run high, find ways for each of you to let off steam. If there are misunderstandings, work to improve communication.

You must also learn to deal with your own problems. Don't let anger and frustration affect your relationship with the consumer or family.

Perceptions

How you see the world depends on where you sit. People see what they want to see. The ability to see situations from another point-of-view can help you solve problems. Understanding the other person's point-of-view is not the same as agreeing with it.

One way to deal with differing perceptions is to discuss them openly, without blaming anyone. Involve parents in the discussion. Agreement will be much easier if they feel ownership of the ideas.

Emotions

Recognize and understand personal and family emotions, as well as yours. Why are you angry? Why are they angry? Are they responding to past grievances?

Talk about everyone's emotions. A good way to deal with anger or frustration is to help individuals and families release their feelings by airing their grievances. Listen quietly without responding to attacks. Many times an apology can diffuse emotions effectively even when you do not acknowledge personal responsibility for the problem.

Communication

Communication is important in resolving problems. There are three basic communication problems: 1) You may not be talking to each other; 2) You may not be hearing each other; and 3) You may misunderstand each other.

What can be done about these three communication problems?

- Be a good listener. Pay close attention to what is said and ask the person to spell out exactly what they mean.
- Make sure the other person understands you.
- Speak for yourself, not for the other person. Tell how the problem affects you and the person who has a disability.
- Be knowledgeable, but don't pretend to know everything.

Preventing Problems

The best way to handle people problems is before they become people problems. Build a working relationship with individuals and families. Get to know them personally.

The next section will address how to build effective partnerships.

Effective Partnerships

"Families and professionals have different relationships with people who have special needs. The family's relationship is personal, lifelong and caring. The professional's involvement is time-limited and objective. Neither relationship is better; they are different. As with most partnerships, bringing people together with differing skills and perspectives can develop a successful relationship.

Key points for developing partnerships:

- While families of people with disabilities may at times be families in crisis, they are not disabled families. They have

capacities for creative problem solving and coping that professionals need to respect, promote and encourage.

- Individuals, families and professionals may have different perspectives, experiences and goals. Sharing and learning to understand these differing perspectives is an important part of care.
- Some decisions may be best made by individuals and family members. Others may need input from a professional.
- In developing a partnership, professionals, individuals and family members should find an appropriate balance of support and dependence.
- Partnership and teamwork between individuals, families and professionals is difficult. The easiest pattern is for the professional to adopt the traditional role of knowledgeable decision maker and others to adopt that of passive recipients. Changing these roles takes commitment by both parties.
- Lack of time and personnel continuity are barriers to communication.
- Professionals need to share large amounts of technical information with individuals and families. To understand technical information, individuals and families should ask questions, read and seek other resources.
- Service coordination should allow professionals to take more responsibility for working with individuals and families, and should also make sure that every individual and family has an advocate.
- Individuals and families do not automatically know how to voice opinions and interact with professionals. Professionals should help individuals and families develop resources within themselves and within the service community.

Source: *Supporting Families With a Child with a Disability*, Alan Gartner, Dorothy Kerzner Lipsky, Ann P. Turnbull (Brookes Publishing Company) 1991.

Working With Families Who Aren't Eligible For DDSN Services

If an individual is not eligible for DDSN services, steps should be taken to assist and refer the individual and their family to other appropriate local, state and/or national agencies.

The referral process should include, but is not limited to:

- Listing the name, address, telephone number and contact person of other appropriate agencies.
- Providing copies of DDSN reports to assist the individual and family when contacting other agencies for assistance.
- Contacting other agencies and informing them of the referral.

Summary

Ten Key Points to Remember in Working With Individuals and Families:

- Remember individuals and families are the experts. You need to learn how to be a consultant to them.
- For there to be an effective partnership between individuals, families and professionals, there must be mutual respect, joint decision-making, sharing of feelings, flexibility and honesty in dealing with each other.
- Meet the needs of the individual/family at their level and at

their pace. Respect the family's dignity and privacy.

- Be knowledgeable about resources available to the individual and their family. Be well-informed of services and resources from other agencies in addition to DDSN.
- Be willing to admit that you don't have all the answers and be willing to get assistance from your supervisor, administrators or other agency personnel.
- Connect individuals and families to others with similar experiences.
- Return phone calls on the same day or the following day.
- Do not keep individuals or families waiting. Their time is valuable.
- If you don't agree with an individual or family: 1) focus on the individual's best interest; 2) emphasize what's right rather than who's right; and 3) begin with areas of agreement and work from there.
- If you are faced with a situation or complaint you cannot handle, talk with your supervisor.

"All of us have dreams, visions and anticipations for the future. Like everyone else, people with disabilities and their families have great expectations. Like everyone else, they too need help to be able to have their expectations come true. Professionals and other people without disabilities also need to have great expectations for people with disabilities. Great expectations include feeling control over one's life, a feeling of meaning in one's life and a sense of one's own value."

Source: Families and Disability Newsletter. Vol. 2, No. 1; Spring 1990. Beach Center on Families and Disability.

Today people bring important gifts to the community. This is true for people with disabilities, as well as people without disabilities. Too often positive contributions made by people with disabilities have been denied or ignored.

We have focused on deficits and negative characteristics and overlooked the gifts and capacities people with disabilities bring to the community. People with disabilities have the ability and right to enjoy the fruits of these contributions. For that reason, all of us should create opportunities for contributions to be given and expectations to be fulfilled.

We need to work together to build on capabilities, adapt environments, build relationships, help individuals and their families identify what is important to them, and empower them with decision-making and spending authority to act upon those choices.

"Visions, dreams, great expectations - the challenge faces all of us. But only if all of us have great expectations for each other, especially for people with disabilities and their families."

Source: *Families and Disability Newsletter*, Vol. 2, No. 1, Spring 1990. Beach Center on Families and Disability.

Appendix

Perceptions of Disability

Traditional

People with disabilities are a burden to their families and society.

Families are dysfunctional because of the burden created by the disability.

Families should have low expectations, expecting segregated services and second-class citizenship, because it's unrealistic for

State-of-the-Art

People with disabilities are valued and contributing members of their families and society.

Society's reaction to and policies about families and disability can create dysfunctionality in families.

Families should have high expectations and skills to obtain integrated services and full citizenship.

them to expect integrated services.

Family Roles

Mothers are most interested in services for the child.

Every family should have the opportunity to designate appropriate members to take on various roles in the child's life.

Parents of adults overprotect them; so adults should be independent from their parents and rely on professionals as family substitutes.

Adults with disabilities have the opportunity to identify and act on preferences for family roles.

Siblings should take responsibility for long-term care of their brother or sister, both before and after their parents' death.

Siblings are entitled to normalization and their own lives. It should not be assumed that they will always have a major role regarding their brother's or sister's care.

If any family member is severely

There are many appropriate ways to support the family so it can provide a supportive home to all members, including the person with a disability.

<p>"distressed" by the person with a disability, separation from the family is acceptable. The person with a disability should be placed outside the home.</p>	<p>Ensuring the person with a disability has a wholesome family life is especially important.</p>
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Source: *Supporting Families With a Child With A Disability*. Alan Gartner, Dorothy Kerzner Lipsky, Ann P. Turnbull (Brookes Publishing Company) 1991.

Myths & Realities

Myths about family participation in the decision-making process:

Myth	Reality
Families are too emotional.	Because of life experiences, families who choose to participate in making decisions are nearly always realistic and knowledgeable.
Families are too closely involved.	Because families are so involved, they make effective decisions. They learn the system out of necessity and can help shape policies and services from their practical needs.
Families are only concerned about their child.	Families involved in policymaking have learned that in helping themselves they may help others.
Families always	Families want some control over services for

want more.	people with disabilities.
Families don't understand or appreciate funding problems.	Families are also taxpayers and don't want to increase spending unnecessarily or irresponsibly. They are usually more sensitive to unneeded expenditures.
Families are troublemakers.	Taking part in decisions that affect the lives of family members is being responsible, not making trouble.
Families expect too much.	Families are aware that good programs and services can maximize a person's potential. Approaching that goal for people with disabilities is cost effective, since they need fewer services when they gain independence.

Source: Adapted from The Speaker newsletter of Sequin Retarded Citizens Association, 6223 West Ogden Ave., Berwyn IL 60402.

Acknowledgments

This guide was developed for professionals of the SC Department of Disabilities and Special Needs to provide suggestions for working more effectively with individuals and their families.

To form effective partnerships between individuals, families and professionals, there must be mutual respect and joint decision-making, sharing of feelings, flexibility and honesty. Professionals, individuals and families need to work together to build capabilities. The challenge faces all of us.

Special Thanks to:

Deborah C. McPherson, Executive Assistant to the State Director and Family Liaison, SCDDSN

Dr. Philip S. Massey, State Director, SCDDSN

Dr. Charles Chadwell, Piedmont Regional Director, SCDDSN

Rebecca Worth-Jones, The Nurturing Center

Colleen Lee, Director, PRO-Parents of SC

Sandy Poole, Parent and Advocate

Sandy Vaughn, Parent and Advocate

Dr. Deborah Valentine, Associate Professor, University of South Carolina - School of Social Work

Jackie Robey, Parent and Advocate

Betty Neff, Parent and Advocate